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ABSTRACT

This paper reports on a long term follow up study of siblings of childhood cancer survivors. Seventy siblings of childhood cancer survivors in 37 families were interviewed using a semi-structured format which included both forced choice and open ended questions. The children discussed their memories of the sibling's cancer diagnosis and treatment experience and its effect on themselves and the family. Subjects ranged in age from 8 to 34, with a median age of 16. The average interval between initial diagnosis and the interview was 12 years. Intensified sibling rivalry and inappropriate guilt fantasies were identified in some siblings, and many stated that they felt excluded from important information about the patient's illness. The importance of open family communication during times of crisis is discussed. (Author/SB)

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SIBLINGS OF CHILDHOOD CANCER SURVIVORS

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When a child is sick, all members of the family are effected; yet few reports have explored the effect of a child's life-threatening illness on the patient's siblings. How does the sibling react to the sick child? What are the consequences of parental preoccupation with the sick child, to the exclusion of the other children; and how do children react to the changes in family routine necessitated by the demands of chemotherapy and frequent clinic visits? How much information about the patient should parents reveal to the well children? What long lasting psychological effects on the siblings result from the illness experience? This paper discusses an investigation of these questions in a long-term follow-up study with the siblings of childhood cancer survivors.

The patients have all survived cancer a minimum of five years beyond diagnosis. Siblings were studied in 37 families, in which the following criteria were met:

1) The patient and his/her parents gave us permission to study the patient's brothers and sisters.
2) All siblings are presently at least 7 years of age.
3) All siblings were available for interviewing (i.e., within a day's travel).
4) All were born before cancer was diagnosed in the patient, with one group comprising an exception to this rule: Because of the chronic, often seemingly unchanging nature of leukemia and its treatment, all sibs of leukemia patients were interviewed, whether or not they had been alive when the patient was diagnosed.

Of the 37 families, all eligible sibs were interviewed in 25 families but in 12 families one or more children were not available for study; usually because they had moved to other parts of the country. In approximately 5 cases we were denied permission to talk with siblings. A total of 70 siblings were

seen, ranging in ages from 8 to 34, with a median age of 16. The median age of the sibs at the time of the patient's diagnosis was 4 years. Well over 50% of the children were pre-schoolers at the time of diagnosis, with only 24 children between the ages of 6 and 17 years at the time. This distribution is not characteristic of the sample as a whole, but is largely indicative of the fact that many older siblings no longer living at home were not available for study.

METHOD

The siblings were interviewed with a semi-structured format including both forced-choice and open-ended questions regarding their memories of the diagnosis and treatment experience and their thoughts and feelings about the effect of the cancer experience on themselves and the patient. In addition all siblings filled out a Death Anxiety Questionnaire. A third of the children were interviewed at the Sidney Farber Cancer Institute, while two-thirds preferred to be interviewed in their homes.

RESULTS

During the time when most of the patients were treated, many doctors at the hospital advised parents not to use the word "cancer" around the patient or siblings. The rationale for this advice was that young children needed protection from such a harsh reality (Evans, 1968). By the time of follow-up, however, 75% of the siblings correctly labeled the patient's disease as "cancer," while some of the younger children used only the word "tumor." Many do not recall how they learned the correct diagnosis. Only 10% indicated an incorrect knowledge of the patient's disease, describing it as a "cyst"

or simply a "sickness." Apparently the "protective" approach was ineffective with most of the children, and probably was not necessary in the first place.

The average interval between initial diagnosis and the time of our study was 12 years. It might be useful to pause a moment and try to remember events in your life which occurred 12 years ago. Not surprisingly, the siblings' memories are closely related to the number of intervening years since the time of diagnosis and their age at the time of diagnosis. One factor caused this trend to vary somewhat. When parents had communicated openly about cancer and the patient's treatment, siblings reported that they "remembered" events which their parents had described to them in conversation. No doubt what they remember is the conversation rather than the event.

Many of the siblings were not able to recall the time of diagnosis but did describe details of the patient's hospitalization or outpatient treatment. While they recalled that household routine was disrupted, most of the younger children feel that this was no more than a temporary upset. Several older children, however, remember that they had to take on adult responsibilities when their parents left them in charge of the healthy children in the family. Some of these respondents described this aspect of the cancer experience with resentment, commenting that they had missed out on some of their childhood as a result. Others recalled that their parents made it up to them later with extra doses of attention when the patient's illness no longer required their undivided attention.

Some siblings who were adolescents at the time of diagnosis felt particularly left out as they did not feel they received adequate support from their parents in this difficult developmental stage. One girl, Sara, told me with great bitterness that after her brother's leg was amputated her parents chose to move to a ranch style house where he could move around more easily. The new home was in another part of town, necessitating a change to a new school

district. Sara bitterly recalls that she was no longer able to see her two best friends, who were primary sources of support for her, and that due to the upset of wondering if her brother would recover or if she herself would get cancer, she was not up to the task of making friends at her new school and neighborhood. She still resents being "shoved into the background."

Several children recalled with disappointment that they were not allowed to visit the patient in the hospital, due to age regulations. Some siblings had problems with other children at school. Occasionally they found themselves having to defend their brother or sister who was ridiculed when cancer treatments left him/her bald or deformed. In a few other cases, misinformed neighborhood parents instructed their children to stay away from the cancer patient's siblings, feeling that they were "contaminated."

Despite such unpleasant occurrences, only about 10% of the sibs described having felt abandoned or left out. The small number of sibs who do remember feeling abandoned suggests that either most parents were able to give their well children an adequate amount of attention, or that the negative effects of the parents' preoccupation with the patient at the time of treatment was not long-lasting.

On the other hand, intensified sibling rivalry was evident in 35% of the cases. One might hypothesize that while siblings are able to accept Mom and Dad's absence, they are sensitive to the quality of the parents' and others' interactions with the patient. One such jealous sibling reported that his brother was "spoiled" and had been given a car and other special presents after undergoing cancer treatment. Another boy is so resentful of his brother that the two are presently undergoing counseling for their disruptive behavior. Only recently did he learn that the reason for the preferential treatment of his sibling was that his brother had cacner. Other siblings (besides the 35% mentioned above) reported that they felt jealous of the extra attention and

special privileges the patient received when he/she was sick, but that now they no longer feel jealous because they understand the reason for the special treatment.

Five siblings described feelings of guilt for somehow causing or exacerbating the patient's cancer. In two cases the sibs believed that they had made the patient get cancer by causing him to fall down. For example, Susie, now 17, has felt personally responsible for her brother's illness since he was diagnosed 13 years ago. When she was four years old her mother instructed her to watch over her infant brother. The baby managed to fall downstairs and when brought to the hospital was diagnosed as having neuroblastoma, a form of cancer. Susie was not told her brother had cancer; she was told by her parents that because of his fall, one of his kidneys had to be removed. Since that time Susie has felt guilty for having "caused" her brother's condition. Thirteen years later she learned that he had been treated for cancer. Since no one told her that cancer is not caused by a fall, she naturally assumed that she had caused his malignancy.

Another girl superstitiously feels that her brother got cancer "as a lesson to me," though she did not elaborate on what the lesson means to her, or why she feels this way.

Every sibling who described feelings of guilt also indicated that neither the subject of cancer nor feelings in general were open topics of conversation in their families. We hypothesize that these two conditions are related. That is, while a lack of open family communication may not be a <u>sufficient</u> condition to produce feelings of guilt (since there are far more families with communication problems in our study than there are siblings who report feeling guilty), it is probably a <u>necessary</u> condition. Our research supports the hypothesis that a family which openly and actively seeks and discusses valid information is not likely to produce such a detrimental side effect as

guilt-ridden siblings. Guilt is born of unchecked fantasy; fantasy is brought to earth when valid information is available to healthy individuals.

Most of the siblings in this study indicated a preference for open communication about cancer, no matter how severe the prognosis. They stressed that both the patient and his/her siblings should receive understandable explanations about the illness and its treatment. In several families the parents of older children told some of the brothers and sisters that the patient had cancer, but instructed them to conceal this unpleasant information from the patient. Because the parents were usually occupied with caring for the patient and because there was no program at the hospital for siblings to discuss their concerns with a trained professional, these siblings shouldered a difficult, very private burden. Ironically, this was undoubtedly an unnecessary burden to bear, for John Spinetta has quite convincinly demonstrated that young patients are far more aware of the implications of their illness than parents suspect, and are able to cope with this knowledge in a supportive environment (Spinetta, 1974 and 1977).

The siblings were asked to describe their perceptions of the extent to which cancer had effected the patient's life: his/her personality, goals, activities, and so on. 65% believed that the patient had changed as a result of the disease. Many of the children discussed the patient's self-consciousness about scars or more serious deformities such as the loss of a limb or scoliosis secondary to treatment. Others described the patient as being more shy, more nervous, more tearful, more "emotional," more dependent on parents, or "spoiled." One sib told me that his brother probably "felt doomed to die" and therefore "tried to get in all the experiences he could" while he was still alive. These experiences included running away from home and experimenting with a variety of irresponsible and illicit activities.

Not all effects were considered detrimental to the patient. One child

felt her sister's cancer-induced blindness improved her memory and her hearing. Others said the patient was more courageous or more conscious of taking care of his/her health now. A few noted that the patient is repaying society - for saving his/her life - by choosing a career in medicine. Two sisters believe their brother has a special purpose in life because he was cured of cancer. He is treated as a hero who courageously fought and won the battle against cancer.

DISCUSSION

Because we were not able to obtain baseline data, the retrospective design of this study clearly does not measure cause-effect relationships. At best it provides hypotheses which can be empirically tested when applied to families currently undergoing treatment. In addition, it is valuable in providing for the first time descriptions of the siblings' perceptions of family events during the cancer experience. On one level, the fact that the sibs' memories are probably distorted by the patient's continued remission and the passage of time is probably irrelevant. Their perceptions are their realities. These perceptions can provide clues to clinicians interested in providing improved services to the families of pediatric oncology patients.

Sibling rivalry is a common occurence, not exclusive to the families of cancer patients. Thus in a retrospective study it is difficult to assess the extent to which the cancer experience may have caused intensive sibling rivalry. One can say, however, that a sibling's jealousy hinders the family's efforts at supporting one another and certainly does nothing to improve the already tenuous equilibrium in the family struggling to cope with the enormous crisis of a life-threatening illness. Regardless of what causes excessive

jealousy, it is an undesirable circumstance and steps should be taken to lessen its occurrence in these families.

While few of these children remember feeling abandoned, many sibs reported that they would have preferred to be included in visiting the hospitalized child and in being privy to the diagnostic and treatment details, in age-appropriate terms. Many sibings preferred concrete, valid information to uncertain fantasies. Some of these stated that they wised a professional at the hospital could have been available to give them information and help them confront their fears and concerns. Such a service might help prevent development of inappropriate fantasies, feelings of guilt and jealousy. Fuzzy or outright dishonest communications may have produced psychological damage; whereas no cases support the notion that open family communication produced negative psychological effects. In the absence of any compelling evidence against open communication, it seems logical for caregivers to adopt and evaluate a policy of honest, supportive disclosure. Open communication will not automatically create families who cope well; but in most cases it is probably a necessary, if not sufficient condition for successful coping.

A whole-family approach to treatment seems most efficacious. Such a program would utilize a variety of treatment and support modalities to fit the needs of individual family members and the family as a whole.

Great strides have been taken in the medical treatment of children with cancer, while their psychosocial needs have received little attention. Let us commit ourselves now to treating the whole child and the whole family.

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